



The DSHS Aging and Adult Services has many partners in serving the growing demand for long-term care.



The growing demand for long-term care:

Aging and Adult Services

All of us grow old, and few of us die suddenly. More often, we experience months or years of slow decline in our abilities. This is a time during which we are very likely to need help with the tasks of daily living, and assistance with medications or other health care requirements. If we are fortunate, we will have family members to help us, but even then we may need more care than our spouses or children can provide.

Some of us also need help with the tasks of daily living and health maintenance as younger adults because of a physical or developmental disability, or as the result of a serious accident or illness from which it takes a long time to recover.

The public long-term care system is designed to address these needs for people who are low-income. About 35 percent of the people who receive publicly financed long-term care are adults under 65; approximately 65 percent are senior citizens.

What is long-term care?

Long-term care can take many forms. For some, it means living in a nursing home where there is round-the-clock staff that includes skilled nurses. For others, it may mean having someone come to their home to help with tasks such as bathing, cooking, or laundry. Home care is what most people prefer, and Washington state is a national leader in helping more people - even people who need a lot of care - receive it in their own homes.

There are several other kinds of living arrangements that also provide long-term care:

- Adult family homes are licensed by the state, and each home can have up to six residents. Some adult family homes specialize in caring for people with similar needs, such as adults with

developmental disabilities, elders with memory loss, or younger people with physical disabilities. An adult family home provides a room (often shared), meals, help with activities of daily living, and supervision for those who have diseases such as Alzheimer's. Many people enjoy the family-like setting of these homes, and the close, long-term relationships that develop in them.

- "Boarding Homes" is a licensing term used by the state to describe facilities that are licensed to care for seven or more people. The level of care provided may include limited nursing services, but not 24-hour nursing staff. Facilities licensed as boarding homes include "Adult Residential Care," "Assisted Living," and "Enhanced

Residents Receiving DSHS Services: SFY 2000

DSHS Services by Program	Total Clients
Aging & Adult Services	61,490
In-Home Services	27,070
Assisted Living	4,350
Adult Family Home	4,965
Adult Residential	2,015
Nursing Home	23,575
Adult Protective Services	6,845
Miscellaneous	4,245

Source: The DSHS Client Data Base, Research and Data Analysis FY 2000

Adult Residential Care." These facilities also often specialize in the care of clients with similar needs, such as people with developmental disabilities, dementia, or mental health problems.

- Assisted living facilities - which are not licensed by the state - have become much more numerous in the last few years, and many people appreciate their focus on privacy and independence. (Some of these facilities have contracts with the state, and are licensed as boarding homes.) People who live in these facilities have their own apartments, and usually have a choice between preparing their own meals or eating in a dining room where the meals are prepared by staff. When

people need more care than an assisted living facility provides, however, they are sometimes forced to move to another setting. Sometimes one wing of an assisted living facility is licensed by the state to provide “boarding home” care to clients whose needs include help with activities of daily living.

Long-term care can also include hiring someone to provide care so that a family member can take time off. This is called respite care.

Most of us are in the habit of thinking that the larger the institution, the higher the level of care. We assume that as people become sicker or more disabled, they might move from home to assisted living, to a nursing home, and then perhaps to a hospital for a final illness. But today, more nursing and rehabilitation services are available in settings other than hospitals and nursing homes than ever before. Many people now stay in their homes or in community facilities such as adult family homes until the end of their lives. Home care providers, nursing services, occasional visits to the doctor, and hospice services may provide all the care they need. Advances in medicine and technology have also made it possible for people with various kinds of disabilities to live more independently.

Who pays for and provides long-term care?

Washington’s long-term care system is composed of many partners:

- Families provide 80 percent of all long-term care.
- The federal and state governments share the cost of Medicaid, which pays for long-term care for low-income people. Approximately 60 percent of nursing home care is paid for by Medicaid.
- The Aging and Adult Services (AAS) of DSHS determines who is eligible for government-paid services and helps them make plans for their care, provides consumer protection by licensing and inspecting long-term care facilities, provides case management for clients who are cared for in licensed residential settings, and investigates allegations of abuse and exploitation through its Adult Protective Services and Complaint Resolution programs. The Aging and Adult Services also plays an important role in planning, managing, and continuously improving Washington’s system of long-term care.
- Local (sometimes county-wide, sometimes multi-county) Area Agencies on Aging (AAA) provide ongoing case management for low-income people

Legacy House

A facility of the Seattle Chinatown International District Preservation and Development Authority (SCIDPDA)

Services: Medicaid Assisted Living, Adult Day Health, Senior Nutrition Programs (congregate meal and home delivery), Low-income Housing

Communities served: Primarily King, Snohomish, Pierce counties, predominantly Asian/Pacific Islander community

DSHS clients: 113 per month

Private as well as public clients? No

Year formed: Legacy House opened in 1998, SCIDPDA formed in 1975

Employees: Total SCIDPDA –55/Legacy House-32

Payroll per year: \$2 million SCIDPDA/\$1 million

Total annual budget: \$5.5 million SCIDPDA/\$1.8 million Legacy House

DSHS or federal funding brought into the community through contract with DSHS: \$1.1 million

whose home care is paid for by the government. AAAs may also help finance Senior Centers, meal programs, Adult Day Programs, and information and referral services. Many of these services are provided by local organizations under contract to AAAs, and many have multiple funding sources, including United Way, local government, other charities, and businesses and individuals.

- Paid home care workers provide direct services to clients and work for either for-profit or nonprofit home care agencies, or as independent contractors. (Some home care workers are family members, but spouses cannot be paid for the care they provide.)
- Residential care providers, including nursing homes, boarding homes, adult family homes and other facilities where people live and receive health services.
- Volunteers, many of whom are trained and deployed by faith communities, provide a wide array of services.

DSHS pays for long-term care services only for people who are low-income - or at least, only for people who meet the income tests established by Medicaid. Medicaid eligibility is complex, but generally speaking, a married couple is allowed to own a house, a car, their household goods, and about \$89,000 in other assets, and



Photo by Della Jordan

Saving resources for the neediest

Anita Schmidt, 90, depends upon Medicaid for her support in a nursing home. And it angers her that some people attempt to hide their assets in order to obtain state assistance that people like her need for necessities such as food and shelter. Until 2001 some people did just that by putting their money into annuities such as inheritances for their heirs. That's when the Department of Social and Health Services closed the loophole and required people with resources to pay for their own care so taxpayer money is available to help people who have nothing.

Read KOMO-TV's story on Facing the Future Profiles, located at <http://www.wa.gov/dshs/FacingtheFuture/NewsProfiles>

must have a monthly income less than about \$3,000. A single person is allowed to own a house, a car, their household goods, and \$2,000, and must have a monthly income less than about \$1,800. For those who are savvy about these rules, however, there are ways to shift assets to other family

members or to put them in trusts. This takes advance planning, but it does mean that some people who are not poor manage to qualify for and receive Medicaid long-term care benefits.

The complexity of Medicaid rules makes them a dark mystery for most people. For instance, if someone has a relative who gives them money to pay their rent, this is counted as income, but if the relative pays the rent for them, it is not. And while some people manipulate the rules to shift assets in order to qualify for Medicaid, other families must use a relative's estate to repay the government for the care their deceased relative received. (This is called estate recovery and is required by the federal government.)

Eligibility for Medicaid long-term care services also depends on a person's degree of disability. To qualify, people must need help with basic "activities of daily living" (ADLs) which are bathing, dressing, eating, grooming, hygiene, ambulation (movement) and toileting. Each person is assessed to determine how much help they need (minimal, substantial, or total) to perform these tasks, and care is apportioned on the basis of these needs.

Private long-term care insurance benefits are based on how much help people need with "activities of daily living." Most insurance policies require that

people need help with two or more of these activities in order to qualify for benefits.

There are also needs called “instrumental activities of daily living.” These are defined as necessary shopping, cooking, laundry and housekeeping. Even if people are unable to perform these activities, they still do not qualify for any government help - or for help under the terms of most private long-term care insurance. However, if people qualify for help with “activities of daily living,” they also get help with these “instrumental activities of daily living.”

The most common reason for people being turned down for government assistance with long-term care is that they need help with “instrumental activities of daily living” only.

People who are not eligible for government-paid services can and do, however, get help with information, referrals to caregivers, protection from abuse, and help resolving complaints about the quality of care they receive. In fact, people of every income level benefit from Washington’s strong programs of consumer protection and quality assurance in long-term care, from its complaint resolution services, and from the work of Washington’s long-term care Ombudsman program.

A brief history of long-term care

Washington state is nationally recognized for the quality of our system of long-term care, for the strength of our consumer protection programs, and for our emphasis on helping people stay in their own homes whenever possible. But our system is still evolving, and it is useful to remember how we got where we are today.

Until the middle of the twentieth century, most long-term care was provided by wives, mothers, daughters and daughters-in-law in private homes.

But as our society changed, our system of long-term care began to change, too. As American families became more mobile, the support systems of extended families began to disappear. And as more and more women went to work, the availability of women’s full-time care declined.

The practice of confining people with developmental disabilities and people with mental illness in large institutions also began to change. New medications made it possible for people with schizophrenia and other mental illnesses to live in the community. Many people with developmental disabilities were found to be more capable of learning and working than people had thought, and they, too began to leave institutions and become more integrated into community life. Even those who couldn’t work often preferred community-based living arrangements that were

more natural - and usually less expensive - than living in large institutions.

At the same time, medical, public health, and nutritional advances meant that people began to live longer. New medical techniques and technologies also meant that people survived more severe injuries - injuries that often left them with major disabilities. So, at the same time that the family-based and institution-based care system began to unravel, the need for long-term care mushroomed.

In 1965, the U. S. Congress created both the Medicare and Medicaid programs. Medicare’s purpose was to provide insurance for hospital and physician care for all seniors, regardless of income, financed by a payroll tax on all workers. Medicaid’s purpose was to provide comprehensive health care - including prescription medications and dental care - to the poor and to people with disabilities of all ages. But instead of relying on a payroll tax, Medicaid is paid for by a 50/50 combination of federal and state tax revenues. These programs have made an enormous difference to seniors - especially low-income seniors - and to people with disabilities who live in poverty.

One of the unintended consequences of Medicaid, however, was an enormous increase in the number of nursing homes. This happened because nursing home care for low-income people was now paid for by the government.

In Washington state, the number of people in nursing homes rose rapidly. But many of the people in nursing homes didn't want to be there, and many didn't really need the expensive, skilled nursing services that nursing homes were designed to provide. People went to nursing homes because there weren't any other options for low-income people who needed help with ordinary tasks of daily living and didn't have family or friends to help them.

The vast majority of people in nursing homes were seniors, but low-income younger people with physical disabilities ended up in nursing homes, too. For them, prolonged isolation from people of their own generation was particularly painful.

Consumer complaints about the quality of care, the low wages and high turnover among nurses' aides, and the institutional quality of life in nursing homes grew just as quickly as the industry itself.

Washington takes the road less traveled

In the early 1980s, Washington diverged from the path taken by most other states. We set out to create a menu of long-term care options that would provide more consumer control and choice. Our state created pioneering programs to help people stay in their homes and live as independently as possible. Spurred by citizen activists, we instituted more aggressive consumer protection

measures to improve the quality of life of people who live in nursing homes and other residential facilities.

This vision of a new, more diversified long-term care system was driven both by consumer demand and by the recognition that nursing home care is very expensive. Nursing homes were established to be medical institutions - modeled on hospitals, but with a lower level of care. Medical institutions are notoriously costly places to live. But they were increasingly serving people whose basic needs were residential - that is, people who needed a place to live where they could get some help with tasks of daily living, some human companionship, and have someone to ensure that when they needed medical care, they got it. Washington's policymakers con-

cluded that more people could be served - and served in the way they prefer - by decreasing the use of nursing homes, and increasing the number of low-income people who are served less expensively in their homes or in other residential settings.

At the same time, Washington also developed a more consumer-focused and aggressive system for assuring the quality of care in nursing homes and other residential facilities.

This ambitious agenda has put Washington far ahead of most of the nation, and our long-term care system has been both honored and emulated.

Washington's pioneering role has also benefited middle- and

Heritage House at the Market, Seattle

Services: Assisted Living

Communities served: Seattle

DSHS clients: 43

Private as well as public clients? Yes

Year formed: 1990

Employees: 36

Payroll per year: \$700,000

Total annual budget: \$1.6 million

DSHS or federal funding brought into the community through contract with DSHS: Medicaid Community Options Program Entry System - Approximately \$1 million per year.

Enjoying life at 94



Photo by Damian Mulinix
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Margaret Jensen's family feared the 94-year-old woman would not recover following a stroke in December 2001. But now she is enjoying life and even able to do jobs such as wiping tables and sweeping floors. She is a resident of the Sharon Care Center, a partner of the Department of Social and Health Services and the only residential care center in Lewis County that cares for elderly people with dementia.

Read the *Centralia Chronicle's* story about this special home on Facing the Future Profiles, located at: <http://www.wa.gov/dshs/FacingtheFuture/NewsProfiles>

upper-income people who don't qualify for government help by fostering the development of home care, respite care, and alternative living arrangements such as assisted living, and by working to improve the quality of care in nursing homes and other facilities licensed by the state.

Although many incremental steps have led to the development of Washington's distinctive

approach to long-term care, one major policy decision stands out as an important leap forward. Beginning in 1983, the federal Medicaid program allowed states to apply for special waivers of the rules, and to use Medicaid funds for care in settings other than nursing homes. Washington applied for and received one of the first COPEs waivers, which meant that state funds would be matched dollar for dollar by the federal government to support caring for people in their homes or in community residential settings.

Another leap forward in long-term care came in 1986, when DSHS's Aging and Adult Services decided to pool funding and combine organizational authority over both nursing homes and home and community care. This meant that decisions about where people should receive care could be based solely on the client's needs and preferences - not on the amount of funding available for a particular kind of care.

In most states, the budget allocations and organizational authority for nursing homes are still separate from the systems set up to provide home and community care. This means that nursing homes and home and community care compete in state legislatures for funding - and home and community care often loses. In most states, about 80 percent of the long-term care budget is spent on nursing home care; in Washington, only about 60 percent goes to nursing homes.

The result of these and many other changes is that Washington's use of nursing homes continues to decline. We serve more people at home and in community residential settings, thus saving money, making it possible to serve more people, and helping clients preserve their independence and privacy.

Work in progress:

Changing the way we think about long-term care

Still, in spite of the fact that we're ahead of most states, Washington's long-term care system is a work in progress. By continuing to expand our capacity to care for people in their homes and in other community settings, we could further reduce reliance on expensive nursing homes, and provide long-term care services to more people.

Already, people are changing the way they think about and use nursing homes. More and more often, people go to nursing homes for just a brief stay (usually after being in a hospital) rather than being there for months or years. Only those with high needs for medical and nursing services that can't be met in any other setting stay in nursing homes for longer periods of time.

In at least a few instances, nursing homes are also changing. A handful of pioneering nursing homes have transformed their facilities into more home-like settings by providing

private rooms and more natural social groupings of residents. They have put social workers rather than nurses in charge of coordinating care - a big cultural change for a traditional medical institution.

People have argued for years about the “medical model” versus the “social model” of how people who are chronically ill or have disabilities should be cared for. What the pioneers have recognized is that this is not an either/or choice, and that the real challenge is to integrate both. People with disabilities and the elderly need health care and a place to live that respects their needs for independence, privacy, assistance, and companionship.

Integration of care also requires changes in the way people are assessed, and in the way long-term care is delivered at home or in community residential facilities. Today, people’s needs for help with activities of daily living are checked off on an assessment form, and a score is assigned based on how much help they need with how many activities of daily living. This score determines how many hours of home care they can receive. But people with complex medical, cognitive, and functional needs may not simply need more hours of care, but different kinds of care, provided by people with different levels of skill or different kinds of training. To address this problem, AAS is developing a new way of assessing people and creating care plans for

them. AAS is also working to integrate the health care services provided by Medicare and Medicaid, so that the medical needs of people receiving long-term care are better managed.

Another gradual change in thinking is beginning to reduce the tug of war between institutional care versus home and community care. Now, rather than posing this as another either/or choice, there is a recognition that care can take place in many settings. Most people want to live and receive services at home. But whether people stay at home, in a residential facility, or in a licensed nursing home is less important than whether they are safe, happy, and able to live life as fully as they can - and whether the state can afford to pay for their care.

Barriers to success

Many barriers stand in the way of realizing this vision of an affordable system that is focused on the needs of the whole person. The most formidable barrier is the rapid growth in the number of elderly people, and the collision between growing demand and declining resources.

The quest for a system that addresses the needs of the whole person is also stymied by rules about what is “medical” and what is not. A low-wage home care worker can remind clients to take their pills, but he or she is not allowed to actually put the pills in their hand or mouth; only a registered nurse is allowed to do

that. In some instances, nurses may train less-skilled workers to perform such tasks, but what is really needed is a more systematic look at how home care is staffed, how home care workers are trained, what they are authorized to do, and how much they are paid.

Most home care workers and agencies believe there is a need for more nursing services to provide for the medical needs of their clients, but they report a shortage of skilled nursing services for long-term care clients who live at home or in community residential settings.

Lack of communication between physicians and the long-term care system is also a barrier. Many doctors are unaware of the existence of alternatives to nursing homes, and when it’s time to discharge a patient from the hospital, they often send them to nursing homes even though a less expensive venue might be preferable.

Another barrier is the way funding is focused on the most vulnerable. While the priority on serving the people with the most needs makes practical and ethical sense, it echoes the failing of our health care system: we focus most of our resources on helping people after they get sick or hurt, and consequently we never have enough to do a good job of preventive care. For instance, a low-income elderly person who lives in a second floor

apartment and has trouble climbing the stairs - but is able to perform all the other “activities of daily living” - will not receive any government-paid help. If, however, she falls down the stairs and breaks a hip, the government will pay for her hospitalization, rehabilitation, and long-term care.

When policymakers tried to address this problem, however, there was a major unintended consequence. In the 1960s, the state legislature created the Chore Services Program, which was designed to address the needs of low-income people who needed help with household tasks such as yard work, household maintenance, shopping, and housecleaning. So many people applied for this program that the funding simply couldn't keep up with the demand. Policymakers call this “the woodwork effect” - the tendency for people to “come out of the woodwork” to apply for programs that address a big unmet need.

Policymakers and budget writers still struggle to find the balance between funding adequate prevention programs, while not spending scarce dollars to provide services to people who could get along without them.

The challenges ahead

Litigation

Most people want to be able to choose who will care for them, and they want to be able to choose family members as paid caregivers. This raises thorny issues about who should be liable when things go wrong. Recent court decisions have held that if the government pays the caregiver, the government is responsible for his or her actions, even if the caregiver was chosen by the client.

Government agencies have conflicting responsibilities: They must protect clients from harm, respect clients' rights to freedom of choice, and, at the same time, protect taxpayer dollars from expensive lawsuits that may result in multi-million dollar judgements against the state.

The best protections against lawsuits are well-designed systems, good planning, and careful and frequent oversight of client care. Care planning and oversight is usually provided by case managers, whose time is always in short supply. Washington's standard is one case manager for every 85 in-home long-term care clients, but the current budget does not support that level. Case management services for people served in nursing homes and residential facilities are also in short supply.

These shortages are compounded by the fact that the complexity and neediness of long-term care

clients is increasing. As people live longer, and as medical advances slow the progression of disease and disability, the number of medically fragile and extremely vulnerable clients is increasing in all care settings.

Harm to vulnerable adults can be prevented by concerned neighbors, vigilant family members and friends, and an aggressive Adult Protective Services program that intervenes immediately when there are indications of exploitation or abuse. Washington has one of the nation's best abuse reporting and interventions systems, but it is dependent on the vigilance of ordinary citizens, and on their willingness to make a phone call when they suspect that someone is the victim of abuse, neglect, or exploitation.

The looming crisis in health care

People who need long-term care are often very medically vulnerable. When doctors disappear from their communities, it causes major life crises. Inability to afford prescribed medicines (among those who don't qualify for Medicaid) can also lead to health crises that are life-threatening and result in pain, suffering, and expensive hospitalization.

These problems are getting worse as Washington's health care system - and in fact, our national health care system - heads toward another crisis.



Americans now use more prescription drugs - and more expensive drugs - than ever before. Among people who need long-term care, the use of prescription drugs is, of course, much higher than the average.

The cost of health insurance is rising, and more employers are passing along a larger portion of these costs to their employees. Doctors have been pressured by managed care organizations to do more for less. At the same time, the number of people who lack health insurance is beginning to rise again. Medicaid and Medicare contribute to this crisis because they pay doctors and hospitals less than private insurance

companies for the same services. Some of the cost of medical care for the poor - both those who have government-paid insurance and those who have no insurance - is shifted to doctors and hospitals, and to ever-more expensive private insurance.

Many clinics and hospitals that have accepted Medicaid and Medicare patients are in financial crisis. Clinics have closed, and doctors have left their practices. In some areas, it is now extremely difficult to find a doctor who will take any new patients, and virtually impossible to find a doctor or a dentist who will take Medicaid patients. This is true even for people in nursing homes.

The long-term care workforce: wages, training, turnover and supply

In its 2001 session, the Washington State Legislature gave long-term care workers who are paid with state funds a fifty-cent-an-hour raise. Home care workers now make \$7.68 an hour. Many nursing home workers also work for very low wages, and one result is a 200 percent annual turnover in nurse's aides.

In the November 2001 election, Washington voters passed an initiative that established a board, appointed by the Governor, that will set standards for training, require criminal background checks, and allow the establishment of unions for home care workers. (Criminal background checks and some training are already required for home care workers who are paid by the government.)

These steps will not be enough, however, to forestall a shortage of home care workers and nursing home staff in the coming decade.

Most people agree that long-term care workers ought to receive better wages and benefits. But if wages were higher, government could afford fewer hours of care for people who need it.

Finding a home care worker already takes time - sometimes a month or more. Home care involves

intimate relationships between clients and workers, so it's especially important - and sometimes very difficult - to find the right matches between workers and clients. And turnover among home workers is high, making it hard to provide clients with continuity of care.

Nursing homes and other residential care providers may also suffer from staffing shortages, and from difficulties maintaining the quality of care because of staff turnover.

Coordinating care for people with multiple care needs

Some people have multiple care issues, including physical and/or developmental disabilities, dementia, mental illness, and chronic physical illnesses. For example, a frail, elderly, mentally ill person with diabetes may be released from prison and require long-term care; a middle-aged person with Down Syndrome and Alzheimer's might need care when her parents pass away; or a younger person with a physical disability might need drug or alcohol treatment as well as treatment for depression and help with tasks of daily living.

The more complicated someone's needs are, the more time must be spent coordinating the different aspects of his or her care. This requires more conversations between more people who come from different disciplines, agencies



Photo courtesy DSHS Aging and Adult Services

and departments - nurses, doctors, mental health professionals, social workers, home health workers, and, of course, clients and their families. People have to establish who will be responsible for various tasks, and which program will pay for which services. There are often points of friction between some of the people and agencies involved in these complex arrangements.

Different programs have different budgets, and thus each has an incentive to try to conserve their resources by shifting responsibility for clients to other programs. People from different disciplines - mental health, medicine, and geriatrics, for example - also speak different languages and have different habits of mind. They may not understand the priorities or points of view of people in other programs or at other levels of government. For families, clients, care providers, and other staff, this can create a truly bewildering and frustrating situation.

To alleviate that confusion and frustration, DSHS has created "A Teams" composed of representatives from the whole spectrum of programs involved in long-term care. The membership of these teams varies from one local area to another, but they generally involve various divisions and programs of DSHS, (Mental Health, Home

and Community Care, the Developmental Disabilities Services, and the Division of Alcohol and Substance Abuse), local Area Agencies on Aging, the Department of Corrections, local law enforcement, and other local human services agencies.

These A Teams meet twice a month and discuss coordination of care for specific clients with complex needs. Participants report that these teams have made an enormous difference both in meeting the immediate needs of specific clients, and in building cooperative relationships and deeper understanding of what different disciplines and agencies can contribute.

Still, everyone also acknowledges that there is much more to be done to dismantle the barriers between different systems. This will require not only coordination among all the people involved in caring for clients, but also system changes that address the incentive to shift costs from one program to another.

Meeting the needs of younger people with disabilities

Young adults with disabilities often place a higher value on personal independence and control of decision making than older people do. Many, for instance, intensely dislike the term “caregiver” and prefer that the people who work for them be called “personal assistants.” To them, the term “caregiver” implies helplessness, dependence, and an obligation to be grateful for the “care” that is “given” by a paid employee.

Some disability rights advocates want less government control over what services they receive, and they object to paternalistic or condescending attitudes. They also have greater needs for specialized assistive technologies that are often not paid for by government programs.

Some states are experimenting with “cash and counseling programs” that give people with disabilities a cash grant, and some training in how to hire and fire staff and manage the paperwork necessary to be an employer. Most states, however, are reluctant to provide these arrangements because they worry that they will be held accountable if a caregiver does something wrong. Washington does not have such a program.

Caring for people with Alzheimer’s disease and other forms of dementia

As people live longer, more people suffer from Alzheimer’s disease and other forms of dementia. In fact, about 50 percent of all people over the age of 85 - a very rapidly growing sector of our population - suffer from some form of dementia. These diseases are not classified as mental illnesses, but in the past many people with dementia were housed in mental hospitals. Some still are. As Washington moves away from institutional care and closes wards in our mental hospitals, more people with dementia are being placed in home and residential care settings. Many of them have behaviors that make them hard to care for, and some of them have other medical and mental health conditions.

In addition, many people with dementia simply wear out their family members and other caregivers. The health and well-being of the elderly spouse of someone with dementia can be seriously damaged by the burden of caring for that person. It is also often hard to find and keep paid caregivers or respite services when the symptoms of dementia include hostility, paranoia, or combative behavior.

Coming soon:

The demographic bulge of the baby boom

Today’s system of long-term care is already stretched to the limit by the growing proportion of our population that is elderly, and the growing number of people who have disabilities and/or chronic illnesses.

But in a few years, today’s problems will be dwarfed by the aging of the baby boom generation. This is a problem not just because of the huge number of people in this generation, but also because of the specific characteristics of the boomers.

Many of this generation do not have employer-paid pensions, and will not have been able to save money for their retirement. A higher proportion of them may need government help beyond their social security checks. Very few people in this generation are buying long-term care insurance. They tend not to recognize that they are likely to experience a period of long, slow decline in their health - a period during which they may need long-term care for several years.

At the same time, boomers are more likely to have higher expectations and a sense of entitlement to high quality, government-paid services.